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Impact of a diagnosis of polycystic ovary syndrome on diet, physical activity and contraceptive use in young women: Findings from the Australian Longitudinal Study of Women's Health

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Running title: Impact of PCOS diagnosis on behaviour

Abstract

Study question: Does diet, physical activity and contraceptive use change after receiving a diagnosis of polycystic ovary syndrome (PCOS)?

Summary answer: Using longitudinal data 12 months apart, young women newly diagnosed with PCOS were more likely to stop using contraception but did not change their physical activity or vegetable intake.

What is known already: Diagnostic criteria for PCOS have widened to capture more women, despite limited evidence of the benefits and harms. Possible benefits of a PCOS diagnosis are that it may help women with family planning and motivate them to implement healthy lifestyle changes to reduce the reproductive, metabolic and cardiovascular risks associated with PCOS. However, there are no empirical studies investigating how women respond to a diagnosis of PCOS with respect to their health behaviour, and longitudinal population-based studies are lacking.

Study design, size, duration: This is a longitudinal analysis of two waves of data collected 12 months apart from the cohort born 1989-1995 in the Australian Longitudinal Survey on Women's Health, a population-based cohort study.

Participants/ materials, setting, methods: Women who responded to the 2014 survey (aged 19-24, n=11,344) and 2015 survey (aged 20-25, n=8,961) were included. Using logistic regression, multinomial logistic regression and linear regression, change in vegetable intake, physical activity and contraceptive use were compared for women newly diagnosed with PCOS to women not reporting a diagnosis of PCOS. Changes in psychological distress and BMI were also examined.

Main results and the role of chance: Young women reporting a new diagnosis of PCOS were no more likely to increase their vegetable intake or physical activity than women not

reporting a PCOS diagnosis. Women newly diagnosed with PCOS were 3.4 times more likely to stop using contraception during the 12-month study period than women without PCOS (14% vs 4%, 95% CI=2.3 to 5.1, p<0.001). This difference remained significant after controlling for demographics, chronic conditions associated with PCOS, endometriosis, body mass index and psychological distress (p<0.001).

Limitations, reasons for caution: All data was self-reported including PCOS diagnosis, assessment of diet quality was limited to vegetable intake only and exact timing of diagnosis within the 12-month period is unknown.

Wider implications of the findings: These findings suggest that a diagnosis of PCOS may not produce short-term benefits by way of improving health behaviour. The observed reduction in contraception use suggests some women may be at increased risk of unplanned pregnancies, highlighting the importance of counselling about contraceptive needs. Both potential benefits and harms must be considered when determining the appropriateness of a PCOS diagnosis.

Study funding/ competing interest(s): The Australian Longitudinal Study on Women's Health is funded by the Australian Government Department of Health. BWM reports consultancy for ObsEva, Merck, Merck KGaA and Guerbet. No further competing interests exist.

Trial registration number: N/A

Key words: polycystic ovary syndrome/ young women/ diet/ physical activity/ contraceptive use

Introduction

Polycystic ovary syndrome (PCOS) is the most common endocrine disorder in reproductive-aged women, and is associated with adverse reproductive, metabolic and psychological outcomes (Dumesic *et al.*, 2015). The Rotterdam diagnostic criteria (2003) expanded the initial National Institute of Health criteria for PCOS (1991) by including polycystic ovarian morphology (The Rotterdam ESHRE/ASRM PCOS Workshop, 2004), including women with milder phenotypes and increasing the number of women diagnosed (Skiba *et al.*, 2018). This expansion aroused considerable debate, as polycystic ovaries using the 2003 Rotterdam definition are also commonly found in women without PCOS (Duijkers & Klipping, 2010; Lauritsen *et al.*, 2014), raising concerns about overdiagnosis (Copp *et al.*, 2017). The rationale for the expanded criteria was to capture the broad clinical expression of PCOS (Dumesic *et al.*, 2015). It is posited that knowledge of a PCOS diagnosis might motivate women to engage in recommended lifestyle changes (Banting *et al.*, 2014), reducing the potential risks of long-term consequences, such as insulin resistance, obesity and type II diabetes (Cooney & Dokras, 2018; Gibson-Helm *et al.*, 2017). Additionally, a diagnosis of PCOS may improve access to treatment, such as the oral contraceptive pill to help manage hormonal symptoms (e.g. irregular menstruation, acne, hirsutism) and reduce the risk of endometrial carcinoma (Teede *et al.*, 2018). However, the criteria have expanded despite a lack of clear evidence of meaningful benefits in terms of reduced risk of adverse outcomes for those newly diagnosed. Additionally, neither the potential benefits nor harms of this expanded definition have been rigorously investigated (Copp *et al.*, 2017).

Whether a PCOS diagnosis actually results in healthier behaviour remains unclear. The limited research available suggests that a PCOS diagnosis could positively impact diet but

also negatively impact perceived weight control and potentially even lead to disordered eating (Lin *et al.*, 2018; Moran *et al.*, 2017). A cross-sectional study of women aged 31-36 years in the community found that women with PCOS were more likely to use both healthy (e.g. reducing meal size, fat or sugar intake) and maladaptive (e.g. use of laxatives, fasting or diuretics) weight loss methods than women without PCOS (Moran *et al.*, 2017). Studies examining weight-related beliefs have also found that women with PCOS are aware they are at higher risk of obesity and associated diseases (Lin *et al.*, 2018; Moran *et al.*, 2010), but perceive poorer control over their weight and fewer benefits of healthy behaviours on weight gain compared to women without PCOS (Lin *et al.*, 2018). Conversely, studies in other conditions suggest that communicating personalised risk information or giving a chronic disease diagnosis has no impact on health-related behaviour (Dontje *et al.*, 2016; French *et al.*, 2017). Longitudinal research is needed to examine the impact of a PCOS diagnosis on health behaviour.

Despite hormonal contraceptives being first-line treatment for regulating hormonal aspects associated with PCOS (Legro *et al.*, 2013; Teede *et al.*, 2018), previous cross-sectional studies of women aged 18-23 and aged 28-33 have found that women with PCOS are less likely to report using contraception than their peers (Joham *et al.*, 2014; Rowlands *et al.*, 2016). However, the extent to which this is due to diagnosis of the condition is unclear, as contraceptive use prior to diagnosis was not assessed. Further investigation of change in contraceptive use after a diagnosis of PCOS is warranted.

Given the limited knowledge of the impact of a PCOS diagnosis on health behaviour, the purpose of this study was to examine whether there were significant changes in young

women's behaviour after receiving a diagnosis of PCOS, compared to women without PCOS. This paper uses a national, longitudinal cohort study of young Australian women to examine changes in vegetable intake, physical activity and contraceptive use over a 12-month period comparing women newly diagnosed with PCOS to women without PCOS. Changes in body mass index (BMI) and psychological distress were also examined as secondary outcomes.

Materials and methods

Study design

Data used in this study are from participants in the cohort born in 1989-1995 of the Australian Longitudinal Study on Women's Health (ALSWH), a prospective study about women's health and wellbeing. Participants were recruited through conventional advertising and online social media platforms (Mishra *et al.*, 2014). Eligible women were living in Australia, held a valid Medicare number, and consented to data linkage with administrative health data. Women received the first web-based survey in 2012-2013, with intended annual follow-up. Further details on survey methodology can be found at www.alswh.org.au.

Ethics approval

The study was approved by the Ethics Committees of the Universities of Newcastle and Queensland, as well as the Australian Department of Health and the Australian Department of Human Services. Informed consent was implied by completion of the survey. To obtain access to the data, a detailed application form outlining the study's rationale, research questions and analysis plan was submitted to and approved by the ALSWH data access committee.

Participants

A total of 17,015 young women completed the baseline survey (first wave) in 2012-2013 when they were aged 18-23 years (see Figure 1). In the current study, data from women who responded to both the second wave in 2014 (aged 19-24) and third wave in 2015 (aged 20-25) were used. Vegetable intake was not measured at baseline, so the first wave was not used in the current study. For clarity, the second wave and third wave will herein be referred to as Time 1 (T1) and Time 2 (T2). As our research question focused on those with a new diagnosis of PCOS (at T2), participants who reported a diagnosis of PCOS at T2 but not T1 were included in the analysis, along with women not reporting PCOS at either time point. Thus, our analysis included data from 7,170 participants.

Measures

Diagnosis of PCOS

Participants were asked "Have you ever been diagnosed or treated for polycystic ovary syndrome?" at T1 and T2. A transition variable for PCOS status was created, with responses coded as 'No reported PCOS' (participants who did not report a diagnosis of PCOS at either time point) or 'New PCOS' (participants who first reported a diagnosis at T2).

Main outcomes

Vegetable intake

Participants were asked how many serves of vegetables they usually eat each day. Scores on a 7-point scale (1=none, 2=less than 1 serve, 3=1 serve, 4=2 serves, 5=3 serves, 6=4 serves, 7=5 serves or more) were categorised into either "meets" (4 or more serves of

vegetables/day) or "does not meet" recommendations based on Australian dietary guidelines (NHMRC, 2013). Vegetable intake has been found to be an important indicator of diet quality (Aljadani *et al.*, 2013; Ledoux *et al.*, 2011). A transition variable was derived to identify participants who at T2 either started meeting recommendations, did not change their intake, or stopped meeting recommendations.

Physical activity

Physical activity was measured using the validated and widely used self-report Active Australia Survey (Brown *et al.*, 2008; Fjeldsoe *et al.*, 2013). Participants were asked to report their frequency and duration of four activities in the last week: walking briskly, moderate leisure activity (e.g. social tennis, recreational swimming), vigorous leisure activity (e.g. vigorous cycling, running) and vigorous household or garden chores (Brown *et al.*, 2012). Minutes spent in each activity was multiplied by a metabolic equivalent score to reflect the average intensity of the activity (x3.33 for walking and moderate activities, and x6.66 for vigorous activities). One metabolic equivalent is defined as energy expenditure at rest (Australian Institute of Health and Welfare, 2004). Scores were then summed to estimate total metabolic minutes/week. Outliers were truncated at 5600 metabolic minutes/week (equating to 28 hours/week of moderate intensity activity). A change score was calculated for each participant by subtracting the summed score at T1 from the summed score at T2.

Contraceptive use

Participants were asked about contraceptive use the last time they had vaginal sex and given a list of six options to choose from: 'the pill', 'condoms', 'Implanon', 'Mirena', 'other contraceptive' or 'none'. Responses at each time point were categorised into either using

contraception (including 'other contraceptive') or not using contraception. A change variable was then generated to identify those who started using contraception, did not change their contraceptive behaviour, or stopped using contraception at T2.

Secondary outcomes

Psychosocial distress

Psychological distress was assessed using the Kessler 10 (K10) scale. The scale consists of 10 items on a 5-point scale (1='None of the time' to 5='All of the time'), measuring symptoms of distress in the past 4 weeks. The items are summed to give a total score, which ranges from 10-50, with higher scores indicating greater psychological distress (Kessler *et al.*, 2003). A change score was calculated by subtracting total K10 at T1 from total K10 at T2.

BMI

Body mass index (BMI) (kg/m^2) was calculated from self-reported body weight and height.

Demographics, possible related factors and covariates

Sociodemographic information was collected in each survey, including age (in years), highest level of education (less than year 12, year 12, certificate or diploma, or university degree), relationship status (single, in a relationship, or separated/divorced), ability to manage on income (easy/ not bad, difficult some of the time, difficult all of the time/ impossible), ever had a live birth (yes or no), and location (urban, rural or overseas). Participants were also asked whether they had ever been diagnosed with or treated for a chronic health condition associated with PCOS (type 2 diabetes, hypertension and heart disease) or endometriosis.

Statistical analysis

Differences in sociodemographic variables at T1 between women newly diagnosed with PCOS at T2 and women without PCOS were assessed using independent t-tests for continuous variables and chi-square tests for categorical variables. Multinomial logistic regression was used to assess change in vegetable intake (increase, do not change, or decrease intake) by PCOS status. Logistic regression was used to assess change in contraceptive use (stop using contraception or continue using contraception) by PCOS status for those using contraception at T1 and not currently pregnant at T2. Multivariable linear regression was used to analyse change in continuous outcomes: physical activity, psychological distress (K10) and BMI. All analyses controlled for baseline values of the outcome of interest. Potential confounding variables measured at T1 were added to the models as covariates in adjusted analyses. Covariates were selected based on their known or potential association with PCOS, prognostic importance for the outcome of interest, or because there were statistically significant differences between the groups on this variable at baseline. Stata/IC version 15 was used for all statistical analyses. P values <0.05 were considered statistically significant.

Results

PCOS status

Of the 7,170 women included in the analysis, 222 (3%) reported a diagnosis of PCOS at T2 but not at T1 ("New PCOS"), leaving 6948 (97%) women not reporting a diagnosis of PCOS for the control group ("No reported PCOS").

Baseline characteristics

Characteristics of women at T1 by PCOS status at T2 are presented in Table I. On average, women newly diagnosed with PCOS at T2 had a higher BMI, were less educated and had more difficulty managing on their income at T1 than women not reporting a diagnosis of PCOS. Women in the New PCOS group reported higher levels of psychological distress at T1 and were also more likely to have a diagnosis of a chronic condition associated with PCOS (type 2 diabetes, hypertension and heart disease) and to have endometriosis. The groups did not differ in age, relationship status, area of residence or parity.

Descriptive statistics

Summary statistics for primary and secondary outcome variables at T1 and T2 are provided in Table II. At T2, around 1 in 5 women from both groups met Australian guidelines for vegetable intake per day. The majority of individuals in both groups exceeded recommended guidelines for physical activity, although there was large variability (Brown *et al.*, 2012). In the new PCOS group, 27% reported moderate levels of psychological distress, 31% high distress and 23% very high distress, according to K10 scale classifications (Andrews & Slade, 2001). In the no reported PCOS group, 32% reported experiencing moderate, 26% high and 15% very high distress. Both groups included a greater proportion of individuals indicating higher psychological distress than age-matched population data (moderate: 23%, high: 15%, very high: 5%; Australian Bureau of Statistics, 2015). On average, women newly diagnosed with PCOS were in the overweight BMI range, whilst women not reporting a PCOS diagnosis were within the healthy BMI range.

Main outcomes

Change in vegetable intake

In unadjusted analyses, women newly diagnosed with PCOS were no more likely to have increased their vegetable intake (relative to no change) than women not reporting a diagnosis of PCOS (see Table II for proportions & Table III for statistical output). Similarly, women newly diagnosed with PCOS were no more likely to have decreased their vegetable intake (relative to no change) than women without PCOS. When controlling for demographics, chronic conditions, endometriosis, BMI and psychological distress at T1, the results remained statistically non-significant (Table S1, S2, S3).

Change in physical activity

In unadjusted analyses, there was no statistical evidence of a difference in the amount of change in physical activity from T1 to T2 between women newly diagnosed with PCOS and women not reporting a PCOS diagnosis. Adjustments for demographics, chronic conditions, endometriosis, BMI and psychological distress at T1 did not substantially change the results (Table III).

Change in contraceptive use

Of the women using contraception at T1 and not currently pregnant at T2, 14% of women in the New PCOS group had stopped using contraception compared to 4% of women without a PCOS diagnosis, indicating an absolute risk difference of 9%. In unadjusted analyses, women with a new PCOS diagnosis were 3.4 times more likely to stop using contraception than women without a diagnosis (Table III). After adjusting for demographics, chronic conditions,

endometriosis, BMI and psychological distress at T1, women with a new diagnosis were 3.0 times more likely to stop using contraception than women without a diagnosis.

Secondary outcomes

No significant differences between groups were found in terms of changes in BMI or psychological distress. Adjustments for demographics, chronic conditions, endometriosis, BMI and psychological distress at T1 did not substantially change the results (Table III).

Analysis by BMI subgroup

Post-hoc investigations of changes in vegetable intake and physical activity with regards to different BMI classifications showed no effect modification of PCOS status with BMI subgroup, suggesting that the differences between new PCOS and no reported PCOS groups did not vary as a function of BMI subgroup.

Discussion

In this study, using two waves of survey data from a large community sample collected 12 months apart, young women newly diagnosed with PCOS were no more likely to change their vegetable intake or physical activity than women who did not report a diagnosis of PCOS. Regarding contraceptive use however, women newly diagnosed with PCOS were more likely to stop using contraception within a year of diagnosis than women without a PCOS diagnosis over the same 12-month period. These findings suggest that a diagnosis of PCOS may not produce short-term benefits by way of improving health behaviour to reduce risk of metabolic consequences and could possibly have a negative impact in terms of reducing contraceptive use for women if they are not actively trying to conceive.

Hormonal contraceptives, such as the combined oral contraceptive pill, are recommended first line treatment for women with symptoms such as irregular periods, acne and hirsutism (Legro *et al.*, 2013; Teede *et al.*, 2018). Despite this, the current study found that women reporting a new diagnosis of PCOS were more likely to have stopped using any method of contraception, supporting previous findings in various age cohorts where women with PCOS were less likely to be using contraception than women without PCOS (Joham *et al.*, 2014; Rowlands *et al.*, 2016). Possible reasons for this could be that doctors may counsel women about their risk of subfertility and the importance of family planning. As a result, women with PCOS may be more likely to be trying to become pregnant earlier than their peers. Indeed, a previous cross-sectional study of women aged 28-33 years (Joham *et al.*, 2014) found that women with PCOS were more likely to be trying to conceive than women without PCOS. However, contraceptive use was lower for women with PCOS not planning to conceive as well (Joham *et al.*, 2014). The average age of women in the current study is much younger (22.5 years at Time 2) than the average age (28.7 years) of first-time mothers in Australia in 2014 (AIHW, 2016), suggesting these women may be altering their life plans and trying to conceive younger than women without PCOS. Additionally, many women with PCOS experience fear of infertility and believe their fertility to be reduced (Holton *et al.*, 2018; Varanasi *et al.*, 2018; Weiss & Bulmer, 2011), despite evidence showing women with PCOS have similar numbers of children to women without PCOS (Holton *et al.*, 2018; Joham *et al.*, 2014; Varanasi *et al.*, 2018). A harmful consequence of this may be that they believe pregnancy to be unlikely and therefore they take risks with not using contraception (Jones *et al.*, 2011; Copp *et al*., 2019). This suggests inadequate education about fertility potential, as whilst some may have trouble ovulating and need reproductive assistance, women with

PCOS can conceive spontaneously and therefore need to use contraception to avoid pregnancy if it is not wanted (Holton *et al.*, 2018). The number of women currently trying to conceive was not assessed in the ALSWH study however, so exact numbers are unknown. Alternatively, some of these women may have been diagnosed with PCOS after stopping use of hormonal contraception, as stopping hormonal contraception can reveal PCOS symptoms. More systematic ways of measuring the consequences of being diagnosed with PCOS are needed.

Although it is speculated that patients may view their diagnosis as a "wake-up call" for adopting a healthier lifestyle (Dontje *et al.*, 2016), women in the current study did not become more physically active or improve their vegetable intake after being diagnosed with PCOS. Only 22% of women newly diagnosed with PCOS were meeting Australian dietary guidelines for vegetable intake (similar to those without PCOS [21%]) at T2. These findings differ to the results of a cross-sectional study of women aged 31-36 years, which found that women with PCOS were more likely to be following both healthy (low glycaemic-index diet, reducing fat or sugar intake, or reducing meal or snack size) and maladaptive weight management practices (fasting, smoking, use of laxatives) than women without PCOS (Moran *et al.*, 2017). However, this study is cross-sectional (outcomes measured on a single occasion) so it is uncertain whether these differences existed prior to, or are due to the diagnosis, limiting comparisons with the current study. Though the majority of participants in the current study were already meeting physical activity recommendations, these results are consistent with a growing body of longitudinal evidence showing no change in physical activity after receiving personalised risk information or a chronic disease diagnosis (Dontje *et al.*, 2016; French *et al.*, 2017; Hollands *et al.*, 2016). Furthermore, the results of the

current study support previous findings that women with PCOS experience greater psychological distress than women without PCOS (Dokras *et al.*, 2011; Dokras *et al.*, 2012), which is evident before and after being diagnosed with PCOS (Rowlands *et al.*, 2016) and remains even after adjustment for other demographic and health variables that may contribute to psychological distress. Further investigation of the cause of this increased distress is warranted.

Strengths and limitations

To date, this is the first population-based cohort study to focus specifically on how young women's health behaviour changes after receiving a diagnosis of PCOS, using a prospective longitudinal design. The study used a large, community sample of young women from a national longitudinal women's health survey, which has previously been shown to be mostly representative of the Australian population, increasing generalisability (Loxton *et al.*, 2017). Moreover, the nature of the data enabled comparison of those reporting a new diagnosis of PCOS with a large, age-matched control group over the same time period. Given that it would be unethical to randomly assign participants to receive a diagnosis of PCOS, the prospective design is the best available way of investigating potential causal relations between the diagnosis and outcomes. A limitation of the current study is that all data are self-reported, including PCOS diagnosis, however self-reported PCOS diagnosis has previously been validated in another ALSWH cohort (Teede *et al.*, 2013). The number of women reporting a new diagnosis of PCOS was also relatively small; yet is consistent with analysis of previous waves of the ALSWH (Rowlands *et al*., 2016). Additionally, the exact timing of the diagnosis was not ascertained, so the duration of time between receiving the diagnosis and completing the survey remains unknown. However, the current study

assessed changes over a fixed 12-month period during which any changes as a result of the diagnosis are expected to occur. Nevertheless, there may be other delayed or longer-term effects of receiving the diagnosis (or indeed temporary behaviour changes that reverted within the study period) that have not been captured in the current data. Furthermore, the assessment of diet quality was limited to vegetable intake, which may not have captured other improvements in diet (e.g. reduced snacking or changed carbohydrate intake), although previous research has identified vegetable intake as a key indicator of diet quality (Aljadani *et al.*, 2013; Ledoux *et al.*, 2011).

Implications and conclusions

These results illustrate that a diagnosis of PCOS may not lead women to adopt more healthy, active lifestyles in the months following diagnosis. This could be due to lack of advice and support from healthcare providers (Gibson-Helm *et al.*, 2017), or could be a result of personal barriers and factors. Psychological theories of cognitive bias, such as genetic essentialism, suggest that disease labels can evoke genetic explanations, leading people to believe they have little control over their symptoms such as weight, causing reduced belief in the effectiveness of lifestyle change (Dar-Nimrod & Heine, 2011). These results reflect the challenges with engagement and compliance, underscoring the clinical challenges in PCOS and other chronic diseases. These findings, together with previous literature (Lin *et al.*, 2018), illustrate a need for more tailored support and engagement in behavioural strategies as outlined in new international guidelines (Teede *et al.*, 2018) to increase healthy behaviour in newly diagnosed women and maximise the benefits of knowing this diagnosis. Effective discussions around a new diagnosis of PCOS should also address women's beliefs and perceived locus of control to increase their self-efficacy and

also dispel myths (e.g. the non-evidence-based belief that PCOS causes weight gain or prevents weight loss; Brower *et al.*, 2018; Kataoka *et al.*, 2017). Some of these misperceptions are addressed in the new international guidelines, for example, clarifying that lifestyle interventions are equally effective in women with PCOS compared to women without PCOS and that most women with PCOS achieve their desired family size (Teede *et al.*, 2018). More research is needed to further understand the impact of a PCOS diagnosis on health behaviour in larger samples of newly diagnosed patients employing longitudinal designs. The observed reduction in contraceptive use requires careful consideration, as it could increase the risk of unplanned pregnancies and also prevent women from receiving any benefit from treatment of hormonal PCOS symptoms via hormonal contraceptives. Unintended pregnancies can have an enormous impact on the economic, psychological, social and physical aspects of women's lives (Gipson *et al.*, 2008), so it is vital that doctors reinforce the importance of using contraception for women with PCOS who are not trying to conceive.

In conclusion, these findings suggest that the diagnosis provides limited benefit by way of improving health behaviour or psychological distress but could have a negative impact in terms of reducing contraceptive use for women not actively trying to conceive. Careful consideration of the benefits and harms of the PCOS diagnosis is therefore a priority to ensure benefits outweigh harms.

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Authors' roles

JD, JJ and TC conceived the study. EC provided statistical advice and TC conducted the statistical analyses. TC drafted the manuscript with substantial input from JJ. All authors contributed to the interpretation of the results and revision of the manuscript. All authors read and approved the final manuscript.

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Conflict of interest

BWM reports consultancy for ObsEva, Merck, Merck KGaA and Guerbet. No further competing interests exist.

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